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# **Family carers' perspectives on post-school transition of young people with intellectual disabilities with special reference to ethnicity.**

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## **Abstract:**

**Background:** School leavers with intellectual disabilities often face difficulties in making a smooth transition from school to college, employment or more broadly to adult life. The transition phase is traumatic for the young person with intellectual disabilities (ID) and their families as it often results in the loss of friendships, relationships and social networks.

**Method:** The aim of this study was to explore the family carer views and experiences on transition from school to college or to adult life with special reference to ethnicity. Forty three families (consisting of 16 White British, 24 Pakistani, 2 Bangladeshi and 1 Black African) were interviewed twice using a semi-structured interview schedule. The carers were interviewed twice, Time 1(T1) and Time 2 (T2), T2 being a year later to observe any changes during transition.

**Results:** The findings indicate that although transition planning occurred it was relatively later in the young person's school life. Parents were often confused about the process and had limited information about future options for their son or daughter. All family carers regardless of ethnicity, reported lack of information about services and expressed a sense of being excluded. South Asian families experienced more problems related to language, information about services, culture and religion.

**Conclusion:** The majority of families lacked knowledge and awareness of formal services and the transition process. Socio-economic status, high levels of unemployment and caring for a child with a disability accounted for similar family experiences, regardless of ethnic background. The three key areas relevant for ethnicity are interdependence, religion, and assumptions by service providers.

## **Introduction**

Transition from school to post-school services for young people with intellectual disabilities (ID) has received much attention from researchers (Cooney 2002; Heslop et al 2002; Hudson 2006). Previous research portrays transition planning to be inconsistent and confused (Heslop *ibid*; Beresford, 2004). The need for information about adult service provision has been consistently reported in the literature (Dean 2003; Morris 2002). Post-school provision is limited, with the progression usually being to further education. Chances of obtaining employment post-school are minimal (Beyer and Kaehne, 2008) and options diminish even further after leaving college. The Education Act 1993 and Department of Education and Employment code of Practice (1994) stipulate that a review should be carried out after the young person's 14th birthday, however there is no similar requirement for those leaving further education colleges (Beyer, 2005). Hudson (2006) argues legislation or guidance as to which agencies should be involved in post-college transition is required. Parents and families, not just young people with ID, are affected by transition and should be major partners in the transition process (Morningstar et al, 1996). Parents also undergo considerable levels of stress at this time (Baxter, Cummins & Polak, 1995; Clegg et al, 2001). However this is often overlooked by professionals, and family involvement is often missing from the transition planning process (Morris, 2002).

The existing literature suggests that there are high levels of unmet need in minority ethnic families caring for a young person with ID. As the White Paper 'Valuing People' (2001), and Valuing People Now (2009) highlight that minority ethnic groups are underrepresented in their uptake of ID services. South Asian families with a person with ID report a great need for formal support (Baxter et al, 1990; Chamba et al, 1999; Mir et al, 2001). Parental awareness of specialist services is low and hence there is low usage of family support services, respite care and short breaks (Hatton et al, 1998; Mir, 2001). Higher rates of psychological distress among South Asian carers of children with intellectual disabilities have been found (Hatton et al, 2011). The combination of disadvantaged circumstances and difficulties in securing access

to appropriate services, which are found for the majority of families with a disabled child, was particularly acute for the minority ethnic families (Fazil et al, 2002; Hatton et al, 2004). The aim of the study reported here was to identify the impact of ethnicity on transition experiences. The method involved eliciting the views and experiences of transition, from young people with ID and their family carers. In this paper we focus on family carer's view and experiences.

## **Method**

### **Recruitment of Participants**

This study was conducted in a metropolitan district in West Yorkshire, England. This study was granted full ethical approval by the National Health Service (NHS) Local Research Ethics Committee. Young people with ID and their family carers were recruited through special and mainstream schools, colleges, disability organisations and Social Services. The study focus was on young people of South Asian origin (Indian, Pakistani and Bangladeshi), but included other groups, primarily White British families. Recruiting from different communities enabled an exploration of any differences in access, use of services and experiences of transition based upon ethnicity. A greater number of South Asians, mostly British Pakistani families were recruited compared to other ethnic groups.

Information sheets in English, Urdu, Punjabi, Gujarati, and Bengali were sent out by Social Services to 305 families on their database. In addition, respite care homes for young people, carer groups and organisations, special schools, mainstream schools and Further Education colleges were approached for recruitment. A short information DVD was developed and shown to young people in their schools and colleges prior to seeking to recruit study participants. The video was produced in the same language as the information sheets. Based on their willingness to participate in the study access to the carers was mediated through the school, a requirement necessitated by data protection and confidentiality issues. A total of 98 families expressed an interest and out of this 43 families consented to take part in the study. There were no significant difference between the families, expressing an interest and those consenting in terms of ethnicity or severity of ID. The age group of young people recruited was 14 – 22 years. Including 19-22 year olds allowed us to look at experiences of transition from further education colleges as well as transition from school. The ethnicity of the family

carers consist of White British (n=16), Pakistani (n=24), Bangladeshi (n=2) and Black African (n=1).

## **Materials and procedure**

For the purpose of this study we developed a semi- structured interview schedule for family carers. Items focused on the carer's perception of the young person's social world and future options. The interview was piloted with a small group of family carers (see Pawson et al 2005). Questions related to friends, relationships, family, support networks, educational and recreational activities, transportation, past events and future wishes.

Once the carer and the young person intimated interest in participating, they were visited at home, the DVD was shown and the research project was discussed. Families were contacted by telephone to book a convenient time slot for the interview. In the case of families who were not able to communicate using English language, an interpreter contacted these families by telephone to book for the interview. An experienced interpreter was used in interviews where carers have difficulty in communicating using English language. The carers were interviewed twice, Time 1(T1) and Time 2 (T2), T2 being a year later to observe any changes during transition. The interview themes used for T1 and T2 were exactly the same. All the interviews were undertaken in the home settings of the family, with prior appointment. The time taken for the interviews ranged from 1 to 2 hours depending on the time taken for interpretation. The interviews were audio taped and transcribed verbatim and translated to English where necessary. Ten interviews were translated to English from Punjabi and Bengali. All the interview transcripts were coded. Emerging themes were selected using the method of framework analysis. Framework analysis (Ritchie and Spencer 2002) was developed in the context of applied research. Applied research aims to provide information which is needed and is used for making recommendations and influence outcomes. This method provides systematic and visible stages of the analysis. This involved familiarization with the data, identifying a thematic framework; indexing, charting, mapping and interpretation (see Ritchie & Spencer 2002),

## **Analysis**

All the interviews were conducted by an experienced research associate (NP). The framework analysis is flexible during the analysis process in that it allows the researcher to

collect all the data and then analyse it or do the data analysis during the collection process. In this study, the data analysis was conducted along with the data collection process. All the interviews were conducted using the semi-structured format and the items of the interviews were not influenced by any of the analysis.

All the audiotapes of interviews conducted in English were transcribed by an independent transcribing agency. The interviews conducted in Urdu, Punjabi, Bengali were transcribed into English by an independent interpreting agency. All the transcripts were checked for accuracy by going through the audiotapes by the interviewer (NP) and the first author (RR).

## **Findings**

The interviews were carefully content analysed to identify emerging themes. The framework analysis identified six key themes

1. Transition
2. Formal support
3. Family involvement, expectations and coping
4. Culture, language and acculturation
5. Religion
6. Ethnicity and socioeconomic status

## **Transition**

The findings highlight family carers' experiences over two time points; this includes views of those who had experienced transition and those who had not yet gone through the process. In the second phase of the study, ten young people made the transition from both school and college. Carers' views changed very little over the year, unless the young person had made the transition or was embarking on it.

Carers' interviews revealed a lack of adequate understanding of the transition planning process. Less than half had knowledge of a transition plan. Some parents recalled attending a school meeting but did not think a definite plan was in place. Parents also reported little consultation with the young person in such meetings. Detailed planning was absent, parents of young people who had a few years left in school were generally informed the young person would remain in school until age 19 without being given more information. However s carers of young people who had an average of a year remaining in school appeared to be

more knowledgeable as more detailed transition planning emerged late in the young person's school life. If there was any planning at all it was just before transition. South Asian carers who did not speak English as a first language expressed less awareness of the transition process.

*"I don't know but maybe the teacher will guide us as to what he would do." (CO23 Pakistani Father)*

*"When he was 16, we had a meeting at school with, teachers, but because we decided he would stay until he was 19, we did not get any options." (COBritish White Mother)*

*"There hasn't been a discussion with teacher about his future." (CO24 Bangladeshi Female)*

For young people who moved out of school at T2 the degree of intellectual disability influenced placement. Young people with severe and complex ID were placed in day care centres, although many carers were dissatisfied with this outcome. Lack of satisfaction either related to the specifics of the day care centre, lack of choice or breakdown in service provision. A few carers felt that the day care centre placement was inappropriate, the wide age range of those in the centre, its cleanliness and location were specific concerns.

Transition from college was even more problematic, with some young people being without a placement for periods of up to five months. Dissatisfaction with adult provision was common. Adult respite care posed the most difficulty in terms of carers' perceptions of availability and appropriateness. Carer aspirations and the young person's aspirations seldom matched, as carers tended to express lower expectations. However carers were also conscious of their child's interests and expressed the desire for these to be met within the child's level of ability. Carers had greater expectations when their children displayed a higher level of social competence. Likewise expectations tended to be lower for young people with severe ID.

Parents reported major dilemmas at the time of transition. They may have understood the importance of letting the child become independent but they often do not know whether their child was able to do an activity outside home with their friends or whether it was safe.

Aspirations that their child would learn new skills, be placed in a stimulating environment and would enjoy where they were placed were prioritised by carers.

*“It would be good if he could be independent for himself, get a job and stuff like that.” (CO33 Pakistani Father)*

*“I suppose you just have to take what is offered and hope it is for the best, I wouldn’t like to think of him being at home and doing nothing.” (CO6 British White Mother)*

### **Formal support**

In general, very few families reported accessing a formal support services between T1 and T2 of the study. Some carers had previously accessed or had contact with services at some point in their lives. However for the few who reported involvement at T2, the point of transition appeared to be a significant time for service providers to contact families, as carers reported a greater awareness of their presence.

The level of formal support information and choice provided to families invariably affected transition outcomes. The majority of carers expressed the need for better communication and information about services. There was a considerable lack of awareness about availability of services. Having a key worker, particularly at the time of transition, was a main need voiced by carers. This would help in accessing information and choosing the most appropriate options for their children. For South Asian carers whose first language was not English there was a greater sense of confusion and lack of awareness as to the availability of options.

*“I haven’t looked into it (future options), I have not tried to look for any activities. I don’t know how to approach it because of my language problems.” (CO40 Bangladeshi Mother)*

*“You don’t really get to know ‘awt. You know, you sort of like, like you get told things if it’s coming up, then you get told things.” (CO26 British White Mother)*

*“ I don’t know anything about programmes that he could go to. If he goes anyway, I don’t know how to contact, I don’t know.” (CO31 Pakistani Mother)*



The degree of ID dictated the type of placement the young person received. Placements were also determined on the basis of availability, for example day care centres were the only option for young people with complex health needs. Carers expressed difficulties in accessing particular services, such as respite care. Absence of respite care could mean that the burden of caring for a child with behavioural difficulties became too great.

*“ I asked for respite care a year ago and nothing...and I’m very dissatisfied with the reaction that I got from the social worker. I’m at the edge of saying I can’t cope with it anymore, I want him to go into respite or a group home. But it shouldn’t had to get to this point, I’m so angry about it.” (CO3 British White mother)*

*“We had a word with the social worker and he said no, parents have no choice now, that’s what he said. He said places are limited, they can only send a child where they can find a place. No, we don’t get much support. When he was a kid, yes we did get a lot of support, but once he’s turned 18, he’s an adult, then that’s it, everything stopped.” (CO1 Pakistani Father)*

Access to formal support services also tended to be contingent on severity of need. Young people who had complex needs usually received greater support and had greater access to respite services than young people with less complex needs. The majority of these families were also of Pakistani origin, as most of the young people with higher needs in this sample were from this community.

### **Family involvement, expectations and coping**

*“Families stay together.” (CO28 British Pakistani Mother)*

A sense of family cohesion featured strongly in respondent’s accounts. The immediate family unit, mother and father, was central to the young person’s life. In larger families siblings were also instrumental in giving support, including taking the young person out, babysitting, bathing, dressing and feeding. However support from extended families was not common. This was either because extended families did not live close by or because carers did not wish to burden them. This experience was consistent with both British White families and South Asian families.

*“They have their own problem they have no time to look after her, we have a big family, they have no time, they have their own family.” (CO2 Pakistani Father)*

Although the transition from school brings new challenges for carers, viewing the change as a positive experience helped some carers to cope better. Being able to discuss issues faced as a family was seen as strengthening resolve and making a family more resilient.

*“Everything is a new adventure and different, it is a move forwards. It is an adventure. We’ll take each thing as it comes along, we’ll sit down and explore and get ideas and see how it goes. We’re very much a network for each other.” (CO14 British White Mother)*

Some carers spoke of future expectations, envisaging that siblings would take on more responsibilities when carers were no longer able to do so. These tended to be larger families in which siblings were already very supportive. Another underlying dimension was the cultural expectations of duty and responsibility. The Pakistani and Bangladeshi carers reported greater concern about siblings taking on carer responsibility in the future, compared to the British White carers. They were also less likely to suggest that the young person should move to supported accommodation or residential homes when they got older. Notions of duty varied amongst all families. It is also possible that concepts of independence may have different cultural meanings. South Asian carers had expectations of the young person gaining independence but for them this did not include leaving the home.

Expectations of marriage were expressed by some carers, although these views were mainly held by Pakistani and Bangladeshi carers. Marriage fulfilled a significant cultural expectation for South Asian communities. These carers also had expectations that when married the wife would take over caring duties. This was also the case for disabled young women marrying non disabled men.

*“We can find a partner for him, we can sit down and explain to his partner what he’s lacking....we work with them because he’s got a lot of friends in Pakistan, we might find him a suitable partner.” (CO27 British Pakistani Father)*

*“My Mum and Dad worry about him being on his own. So, that is what we worry. Hopefully when he is 30 he can get married and have a family because that is in our Asian culture anyway.” (CO35 British Bangladeshi Sister)*

### **Culture, language and acculturation**

Family carers who did not speak English as a first language experienced a greater sense of confusion and unawareness of post transition options. South Asian families in general had low awareness of service providers and little understanding of their roles. Competency in English may vary and cultural misunderstandings may arise when words are used which have no direct translation in their language, or if the words used do not fit in their cultural context. These carers seldom used the term intellectual disability, describing their son or daughter as “a little slow” or “has a problem with the brain”. For many families there was also confusion about the identity of professionals, the agency they represented and the appropriate service to approach in order to address specific needs.

*“ I don’t know who, somebody did come, a lot of people visit and have been involved with my older son and all my children but I don’t know.” (CO34 Pakistani Mother)*

Many carers encountered similar problems, but having a language barrier created additional difficulties. Older carers in this study were first generation Pakistani or Bangladeshi immigrants, many of whom did not speak English. Mothers often relied on their husbands or their adult son/daughter to attend meetings and interpret on their behalf. Mothers had the primary role of looking after the children and relied on their husbands to take care of other responsibilities, which allowed for less time to interact socially and created distance from mainstream society.

*“I was looking after the children, my husband went to the school meetings. I didn’t know what to do, I was so busy. I couldn’t ask for help because of my language problem.” (CO36 Pakistani Mother)*

Conversely, the second generation South Asians experienced higher integration as they spoke English, as well as their mother tongue, and had higher levels of educational attainment. Second generation carers also exhibited greater confidence in approaching services and finding out information.

*“I feel sorry for some people who don’t speak English, although these agencies may provide interpreters, those who don’t speak English can’t ask for it in the first place. It’s probably why some have difficulty accessing services.” (CO18 British Pakistani Mother)*

## **Religion**

For many families religious beliefs helped them to cope with their child’s disability. They believed it was God’s will and that they would cope with God’s help. Some carers prayed and hoped the young person would get better.

*“They are God’s angels, they come into the world to get loved, they don’t harm anybody, just to get loved. They are sin free. For everything there is a reason, I don’t worry now but sometimes human nature you wonder why this happens. Deep down you wonder why God, but if God’s happy, I’m happy. These children with special needs are God’s angels....you are blessed with this child.” (CO11 Pakistani Mother)*

But perceptions of shame and the stigma attached to disability were also present. Such feelings made some families feel more vulnerable, causing them to become more secretive and protective of the young person. They felt they had a duty to look after their children and did not wish members of the community to know about their support needs and the details of their child’s disability.

*“Actually they think we brought shame on them.. they don’t say it to your face but I know, when they come round here, you can tell you know.” (CO31 Pakistani Father)*

Religious beliefs may influence both access to services and transition outcomes. Pakistani Muslim parents expressed concerns about the young person being led astray and disregarding religious beliefs and cultural customs in particular settings.

*“If there’s loads of other Muslims there (supported accommodation) and depending on what kind of environment, halal food then maybe. But if there is drinking, going out with girls, I don’t want him, I wouldn’t want him to think that was normal, to drink or whatever.” (CO28 British Pakistani Mother)*

There were also concerns about the vulnerability of females to the opposite sex, and issues of shame were raised. Similar anxieties were also expressed by white carers. Being female and having ID compounds concerns about safety.

### **Ethnicity and socioeconomic status**

White, Pakistani and Bangladeshi families experienced difficulties with transition and service usage. All groups reported limited awareness of service provision. Having a child with a disability might be a more dominant factor in their lives than their ethnicity. There were similarities in the reported experiences of all the families in the study.

*“ When I phoned up social services, who gave me a number to ring, I phoned them who gave me another number to ring and I phoned 8 places and eventually finished up speaking to the same person I were speaking to originally. So from one you have gone round in a big circle to the same office I phoned originally. I got no help.” (CO40 British White Mother)*

*“I don’t know anything about programmes that he could go to. If he goes anyway, I don’t know how to contact, I don’t know.” (CO5 Pakistani Mother)*

Although families shared common needs and experiences of caring for a learning disabled child, there were some differences. South Asian carers expressed greater need for practical and financial assistance, information and guidance, one to one support and help with leisure and transport needs. Some South Asian families reported particular problems with the local authority in obtaining assistance for making adaptations to their home for the young person. Non-English speakers also reported difficulties in claiming their disability benefits, as they found the claim forms lengthy and difficult to fill out. Pakistani families had higher usage of respite services. This may have been related to greater need as the majority of young people with complex needs were of Pakistani origin. Some of the families had other children with ID, increasing their need for respite care.

*“Sometimes they do need somebody to fill in the forms and read the forms for them, you know like letters and that. My Dad doesn’t speak much English but he does a bit. They can speak, they can’t read English, they find it hard.” (CO35 British Bangladeshi sister)*

Socio-economic status and level of education also affected access to services regardless of ethnic background. Carers who were financially stable and in employment tended to access mainstream facilities and had the confidence to seek information about leisure pursuits and group activities, regardless of their ethnic background.

*“I’m quite capable and I do find out my things, I sort of do explore channels.”(CO6 British Pakistani Mother)*

However, a combination of economic deprivation and social disadvantage, language barriers, low educational attainment and severity of disability made the experience more difficult for some Pakistani and Bangladeshi families.

## **Discussion**

Our study found that family carers had limited information and were generally unaware of a transition plan until the young person was on the verge of leaving school. The importance of informal carers in the support of people with ID is well established. Family planning and decision making about transition planning as well as family involvement with the child and service providers are primary factors in transition success (Blacher, 2001). Having helpful social support has much influence on positive well being (White & Hastings, 2005). Majority of carers expressed the need for better communication and information about services. This lack of information made available for young people and their families has been a recurrent problem (Dean, 2003; Morris, 2002). There is also a paucity of specialist staff to work with families around transition issues, and staff cannot cope with the demand for services (Cope, 2003). For carers whose first language was not English, there was a greater sense of confusion and lack of awareness of the future options. Pakistani and Bangladeshi carers in general had low awareness of service that were provided and of the different professionals and their roles.

The degree of learning disability also dictated the type of placement the young person received. Young people with severe and complex ID had little choice in deciding the type of placements or opportunities for fulfilling their aspirations. Limited resources post-college were also problematic as many parents were dissatisfied with adult service placements. Lack of statutory guidance post college may result in these young people experiencing ‘invisible

transitions' (Heslop & Abbott, 2007), that is they have no clear pathways for making the transition once they complete further education courses.

Family carers expressed difficulties in accessing the appropriate services, they disliked the repetition of disclosing problems to various professionals, and they found it difficult to access relevant information about services, all areas that have been well documented. Family carers requested a central point of contact which will help them to raise their issues about transition and better co-ordinate the activities of all the people involved in the transition planning process. A key worker or a liaison worker model works effectively with South Asian families as it provides better relationships and increased engagement with services (Raghavan et al 2009). During transition a key worker may offer support by providing information to carers, link various services involved with the young person, focus on the young person's specific needs and find appropriate options. A minority of carers also felt that they were perceived by service providers as coping and hence as being inappropriate for support services.

Language barriers have been mentioned extensively in the literature (See Chamba & Ahmad 2000), however less attention has been paid to the effects of acculturation and migration. Older people may be less adaptable as the length of time spent in their own culture makes it more difficult to change (Berry, 1997). It is also more difficult for women with domestic responsibilities and young children to find time to learn English informally or attend English class (Henley & Schott, 1999). Research in America carried out by Casado & Leung (2001) indicate that language acquisition was very stressful for immigrant elders because they had fewer resources such as income, and education and lower starting levels of language proficiency in the language they are seeking to learn to help them adapt. South Asian families in particular are often thought to have extensive support networks by professionals. However anxiety about societal attitudes towards disability and the fear of obligation may prevent South Asian carers from seeking and accepting help from wider social networks (Katbamna et al, 2004). Further, it is also crucial for professionals to have knowledge of cultural systems in order to build links into community networks. Family support can both enable and restrict independence. It is important to acknowledge the collective nature of South Asian communities and to recognise that achieving independence for the young person may have a different meaning to these families. Achieving interdependence may be more appropriate (Atkin & Hussain, 2003). The unwillingness by services to engage with South Asian families may result in the family's reluctance to engage in services.

For many carers their belief system provided comfort, this was particularly expressed by Pakistani family carers. Religious beliefs and practices may also cushion stress related to transition (Blacher, 2001) as religion may offer a source of comfort and spiritual connectivity. Religious views could also influence access to services and transition outcomes. Beliefs, attitudes and practices may be incompatible with the services offered and with the transition goals set. This has implications for services, who should have awareness of, and address, these cultural and religious needs. It is important that while service providers address cultural and religious issues they are also cognisant of differences within a particular culture. There is a tendency to make assumptions based on one's culture and beliefs. This has been an area of concern where professionals react to 'differences' without the relevant knowledge. Katbamna et al. (2002) argue that South Asian carers' experiences largely parallel those of others, but there are some issues that are distinct, namely, language and communication barriers, culturally inappropriate services, and implicit or explicit racism. Having an intellectual disability, or having a child with ID, might be a more dominant factor in their lives than the individual's ethnicity. It could be argued that the collective experiences of all the families in our study, irrespective of ethnicity, were very similar. Nonetheless, the added label of 'minority ethnic' further complicates identity and subsequent experiences. Moreover, for the young person, the label of disability is not the only facet in which identity forms, as ethnicity, culture, religion, gender and youth are important in personal identity (Atkin & Hussain 2003; Islam, 2008). Ethnicity is only one part of identity as identity is fluid and continually changes across contexts and time (Karlsen & Nazroo, 2002). There may be variables which are specifically ethnic which may include ethnic identification, perceived discrimination and bilingualism (Betancourt & Lopez 1993). The consideration of ethnicity in transition planning should encompass these various elements.

The relationship between ethnicity and socio-economic status is very complex. Emerson et al. (2004) found a strong link between ethnicity and carer psychological distress mediated by socioeconomic deprivation. There is substantial evidence to suggest that South Asian families caring for a disabled child, experience greater social and financial deprivation (Hatton et al. 2004). Many South Asian communities face inequality in housing, employment and economic disadvantage. Higher levels of unemployment, lack of benefits and racism also adds greater psychological stress to these families (see Hatton et al 2011). It appears that



minority ethnic communities suffer higher levels of poverty, hence untangling the effects of poverty and ethnicity is crucial (Fujira & Yamiki 2000).

As in any research, this study also has limitations. We used a purposive sample for this study. We encountered a number of problems with recruitment. Despite all the best efforts to provide information about this research to young g people and their families for recruitment, many Pakistani families felt that there was too much research with Pakistani families and its failure to achieve adequate service improvements for them contributed to low numbers for recruitment. The sample did not have equal representation of all South Asians in the locality, for example, lack of Indian families and low numbers of Bangladeshi families. The number of South Asians compared to British White families and their gender ratios were unequal. The young people recruited were at different stages in the transition process. Recruiting a greater number of young people (and their families) who were about to leave school in the first phase of this study may have highlighted more differences or similarities between South Asian and British families.

## **Conclusion**

The majority of families in this study lacked knowledge and awareness of formal services and the transition process. Socio-economic status, high levels of unemployment and caring for a child with a disability accounted for similar family experiences, regardless of ethnic background. Less advantaged white families also experienced barriers to accessing formal services and obtaining appropriate support, which suggest that socio-economic factors influence service access. In the context of this study, ethnicity taken as a separate variable was not the sole determinant influencing transition outcomes and service access. South Asian families who had higher socio-economic standing and educational attainment were able to access mainstream activities and seek out relevant information. However, many South Asian families had greater housing problems and higher levels of unemployment than white families. The complex relationship between socio-economic standing and ethnicity warrants further research.

Our study highlights three key areas:

1. South Asian extended family can be a source of support but also anxieties of responsibility and shame can mean that support is not accessed. Service providers

should not make assumptions about there being family support beyond the nuclear family without exploring the complex dynamics of family relations.

2. If our aim is promoting independence, then South Asian understanding of it may be different. Interdependence as a goal of transition planning might be more consistent with family wishes and so more supported.
3. Religion might offer some sense of support in day to day life with consolation and hope. Being a member of a community that is part defined by religion might offer extra human capital but also include, the possibility of feeling you have brought shame to that community.

## REFERENCES

- Atkin, K. & Hussain, Y. (2003) Disability and ethnicity: How young Asian disabled people make sense of their lives. In: Riddell, S. & Watson, N. (Eds), *Disability Culture and identity*. Pearson, Prentice Hill.
- Baxter, C., Poonia, K., Ward, L & Nardishaw, Z. (1990). Double discrimination. London, King's Fund Centre/Commission for Racial Equality.
- Baxter, C., Cummins., R. A. & Polak, S. (1995) A longitudinal study of parental stress and support: from diagnosis of disability to leaving school. *International Journal of Disability, Development and Education*, 42, 125-136.
- Berry, J.W. (1997) Immigration, acculturation, and adaptation. *Applied psychology: An International Review*, 46, 5-34.
- Betancourt, H., & Lopez, S.R. (1993) The study of culture, race and ethnicity in American Psychology. *American Psychologist*, 48, 629-637.
- Beyer, S. (2005) *Rights of people with intellectual disabilities. Access to education and employment*. Budapest, Open Society Institute.
- Beyer, S. & Kaehne, A. (2008) The transition of young people with learning disabilities to employment: what works? *Journal of Developmental Disabilities*, 14: 81-90.
- Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Journal of Mental Retardation* 106(2): 173-188.
- Casado, B.L., & Leung, P. (2001) Migratory grief and depression among elderly Chinese immigrants. *Journal of Gerontological Social Work*, 36, 5-26.
- Chamba, R., Ahmad, W.I.U., Hirst, M., Lawton, D. & Beresford, B. (1999). On the Edge: Minority Ethnic Families Caring for a Severely Disabled Child. Bristol, Policy Press.
- Chamba, R. & Ahmad, W. I. U. (2000) Language, communication and information: the needs of parents caring for a severely disabled child. *Ethnicity, disability and chronic illness*. In Waqar Ahmad(Ed), Buckingham, Open University Press.

Clegg, J., Sheard, C. & Cahill, J. (2001). Severe intellectual disability and transition to adulthood. *British Journal of Medical Psychology* 74: 151-166.

Cope, C. (2003) *Fulfilling lives: Inspection of Social Care Services for people with learning disabilities*. London, Department of Health.

Dean, J. (2003) *Unaddressed: The housing aspirations of young disabled people in Scotland*. Joseph Rowntree Foundation, York.

Department of Education and Science (1993) *Education Act*. London, HMSO.

Department of Education and Employment (1994) *Code of practice on identification of special educational needs*. London, HMSO.

Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st century*. Norwich Stationary Office Limited.

Department of Health (2009) *Valuing People Now: A New three year strategy for people with learning disabilities*. Department of Health: London

Emerson, E., Robertson, J., & Wood, J. (2004). Levels of psychological distress experienced by family carers of children and adolescents with intellectual disabilities in an urban conurbation. *Journal of Applied Research in Intellectual Disabilities* 17, 77-84 .

Fazil, Q., Bywaters, P., Ali,P.,Wallace, L., & Singh, G. (2002). Disadvantage and Discrimination Compounded: the experience of Pakistani and Bangladeshi parents of disabled children in the UK. *Disability & Society* 17(3): 237-253.

Fujiura, G. T., & Yamaki, K. (2000) Trends in demography of childhood poverty and disability. *Exceptional Children*, 66 (2), 187-199.

Hatton, C., Azmi, S., Caine, A., & Emerson, E. (1998) Informal carers of adolescents and adults with learning difficulties from South Asian communities: family circumstances, service support and carer stress. *British Journal of Social Work*, 28, 821-837.

Hatton, C., Akram, Y., Shah, R., Robertson, J. & Emerson, E. (2004) *Supporting South Asian Families with a Child with Severe Disabilities*. London, Jessica Kingsley Publishers.

Hatton C, Emerson E, Kirby S, Kotwal H, Baines S and Hutchinson C (2011) Majority and minority ethnic family carers with intellectual disabilities: perceptions of challenging behaviour and family impact. *Journal of Applied Research in Intellectual Disabilities*, 23, 63-74.

Henley, A. & Schott, J. (1999) *Culture, religion and patient care in multi-ethnic society*. Age Concern, London.

Heslop, P., Mallett, R., Simons, K. & Ward, L. (2002). Bridging the divide at transition: what happens for young people with learning difficulties and their families?, British Institute of Learning Disabilities.

Heslop, P & Abbott, D. (2007) School's Out: pathways for young people with intellectual disabilities from out-of-area residential schools and colleges. *Journal of Intellectual Disability Research*, 51(7), 489-496.

Hudson, B. (2006) Making and missing connections: learning disability services and the transition from adolescence to adulthood. *Disability & Society*, 21(1): 47-60.

Islam, Z. (2008) Negotiating identities: the lives of Pakistani and Bangladeshi young disabled people. *Disability and Society*, 23, 41-52.

Karlsen, S. & Nazroo, J.Y. (2002) Agency and structure: the impact of ethnicity and racism on the health of ethnic minority people. *Sociology of Health and Illness*, 24 (1), 1-20.

Katbamna, S., Bhakta, P., Ahmad, W., Baker, R. & Parker, G. (2002) Supporting South Asian carers and those they care for: the role for the primary care team. *British Journal of General Practice*, 52, 300-305.

Katbamna, S., Ahmad, W., Bhakta, P. Baker, R., & Parker, G. (2004) Do they look after their own? Informal support South Asian carers. *Health and Social care in Community*, 12 (5), 398-406.

Liabo, K. Newman, T, Stephens, J. & Lowe, K. (2001) *A review of key worker systems for disabled children and the development of information guides for parents, children and professionals.*

Mir, G., Nocon, A., Ahma, W. & Jones, L. (2001) *Learning Difficulties and Ethnicity.* London, Department of Health.

Morningstar, M. E., Turnbull, A.P. & Turnbull, H. (1996). What do students with disabilities tell us about the importance of family involvement in the transition from school to adult life? *Exceptional Children*, 62(3): 249-260.

Morris, J. (2002) *Young disabled people moving into adulthood.* Joseph Rowntree Foundation, York.

Pawson, N., Raghavan, R., Small, N., Craig, S. & Spencer, M. (2005) Social inclusion, social networks and ethnicity: the development of the Social Inclusion Interview Schedule for young people with learning disabilities. *British Journal of Learning Disabilities*, 33, 1, 15-22.

Raghavan R, Wasseem F, Newell R and Small N (2009) A randomised controlled trial of liaison worker model for young people with learning disabilities and mental health problems. *Journal of Applied Research in Intellectual Disabilities*, 22, 256-263

Ritchie, J. & Spencer, L. (2002) Qualitative data analysis for applied policy research. In: Miles Huberman (ed). *The qualitative researcher's companion*, London: Sage.

White, N. & Hastings, R.P. (2004) Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17, 181-190.